

A pilot project of Cancer Patient Library in Italy: the results of a customer satisfaction survey and its products.

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A pilot project of Cancer Patient Library in Italy: the results of a customer satisfaction survey and its products

Abstract: The purpose of this study is to determine the degree of satisfaction of the users of the Cancer Information Point (CIP-LP), section of the Library for Patients (LP) active, since 1998, at the National Cancer Institute of Aviano, Italy. The CIP-LP is based on a skilled intermediary, adequate informational material and a specific location, within the Scientific Library of the Institute. **Patients and Methods:** A survey was developed to assess service functionality and quality from the users viewpoint. During a 6 month period, a questionnaire was mailed to 194 patients and relatives who previously used the CIP-LP, 113 (58%) were received and processed. **Results:** 91% of the respondents was pleased with the CIP-LP and 95% of them would recommend the service to other people. The information obtained contributed to a clearer understanding of the illness and treatment (45% as first answer) and to feel a better control of the situation (33%). 51% evaluated the informational material received as “good”, 42% “excellent”, 4% “sufficient quality”. **Conclusion:** This survey makes evident the appreciation and usefulness in the users’ perception of a specific hospital library for cancer patients and their relatives providing an information service supplementary to doctor-patient communication.

Key words: Libraries, Medical; Libraries, Hospital; Information Services; Neoplasms; Patients; Patient Education Handout; Patient Participation; Information Dissemination; Health Care Surveys; Questionnaires; Pilot projects; Internet.

Key points of policy:

1. Cancer patients’ information needs are not necessarily correlated with an unsatisfactory doctor-patient relationship
2. Every user his book. Every book its user. It is necessary to take special care in meeting the information materials needs and the information needs of users when they are patients.
3. It is necessary to know “more” about cancer patients’ information needs, especially in Italy
4. It is essential to expand the international literature in this topic
5. It is necessary to provide Italian patients and their relatives with supplementary information material about cancer, which is both readable and accessible
6. It is easy to reproduce a model based upon three key factors: 1) an adequate place; 2) quality material; 3) an information and communication professional.

Practice Implications:

1. The study demonstrated the quality and effectiveness of a service which became a “model” in the field of information to cancer patients in Italy.
2. Currently there are at least twenty information services in Italy based on this model with many similarities and some peculiarities
3. This service inspired the most authoritative Italian database for cancer patients: “Azalea, a digital library for patients, their families and the general public” supported by Alliance Against Cancer and the Italian Ministry of Health [URL <http://azalea.web.it>]

1. Introduction

The role of cancer patients in health care organisations is more proactive today than it ever was. Patients conduct their own information searches regarding their health using Internet, the media, written materials and other information sources(1;2). There are many studies documenting that effective doctor-patient communication is an essential ingredient of cancer care (3) (4) and information is a key component of such communication. There are also many studies which attest to the fact that information during the course of care is essential to ensuring quality care but often the conclusion is that “future research should examine cancer patients’ information needs and sources throughout their cancer journey”(5). Many information centres or other

similar experiences for patients and the general public, such as telephone hotlines, face-to face information services and web-based services, are present all over the healthcare landscape in Europe and the United States (6-8). The range of experiences differs to no small degree(9). Among these different models there are also the hospital libraries, i.e. "information centers primarily serving the needs of hospital medical staff and sometimes also providing patient education and other services", according to the MESH definition¹. There is not a large quantity of literature about patients' libraries worldwide and this number decreases if restricted to cancer patients libraries. However, among them, there are some prestigious experiences(5;9-23)(11;13;24), discussion lists², and directories. Some of these international reference models, led in 1998 to the establishment of a Library for Patients (LP) at the National Cancer Institute of Aviano, the most north-easterly located of the seven such cancer centres in Italy. Moreover, some hints came from the Italian cancer voluntary associations sphere(25) and from the results of a specific survey of user information needs, previously conducted at the hospital(26). From this survey, carried out on January 1998 with a view to obtaining data useful for the organization of LP project, it emerged that 63% of the interviews - including admitted patients and outpatients - recognised the utility, as registered in the literature - of having informative supplementary material in the hospital (27-29).

The LP project in our Institute was a pilot project in Italy in the field of supplementary information for cancer patients. Our leading hypothesis was that patients' information needs were not necessarily correlated with an unsatisfactory doctor-patient relationship. It is inherent in the nature of a disease such as cancer, and diseases of uncertain outcome, that a patient will manifest behaviours different from those manifested in chronic illness. One such behaviour is the search for further information, beyond that received in the doctor-patient encounter(3;30). The patients are looking for information materials to better understand the experience of their disease "so as to ask better questions and understand their answers" as has often been said. Simply put, one has to find out more so as to maintain control of one's life(31).

The purpose of this study is to determine the degree of satisfaction of the users of the Aviano LP. A specific user satisfaction survey was carried out in 2003 with the aim of gathering patients' opinions and feelings about the information service in order to improve it within an overall vision of Continuous Quality Improvement.

2. Patients and Methods

2.1. *Cancer Information Point: a description of the service*

The LP is structured in two parts: the core is the Cancer Information Point (CIP-LP), the other part is a recreational books' Point. These two parts work together within the context of the biomedical library of the Institute. In the cancer library's vision, according to Ranganathan "Five Laws"(32), patients, their relatives and friends are "simply" particular users of the library who are searching for adequate and appropriate informational materials concerning their illness not only for knowledge but also for better coping with cancer.

A skilled intermediary – at present a psychologist "trained" in information science – is appointed to the CIP-LP, a section of the scientific Library. He provides patients, their relatives and citizens willing to know more about different aspects of cancer and related topics with an adequate "package" of information. The CIP-LP "spirit" is expressed in the great attention paid to the individual's information needs and in the respect shown for the autonomy of the patient and his or her relatives. The material, which for the most part either originates in Italy or has been translated or adapted, is scientifically valid, updated and written in straightforward language. A large part of this material is arranged on the CIP-LP's shelves by class/subject. All the

¹ Cfr <http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=mesh&list_uids=68007992&dopt=Full>

² Cfr.< <http://www.selu.com/cancerlib/index.html> >

documents, both print and electronic - are recorded in an automated archive, merged at present in a national databank of literature for cancer patients, to which has been given the name Azalea (33;34). The service is publicised within the Institute via leaflets and via the Internet web page with a description of the initiative, its services, who it is for, and its opening hours. . The leaflets are made available at the Volunteer Service welcome desk, located at the entrance of the Institute, in the various waiting rooms throughout the building and in the central hall used for patient entertainment and various recreational activities promoted by the Institute and Volunteer Service. The service is also publicised by word of mouth from those who have used the service. The service answers approximately 450 requests per year, but the topics covered number about three times more, since each person typically seeks information on various aspects of disease.

The survey of the CIP-LP was fundamental to monitor over time whether the objective of responding to patients' information needs was achieved. Furthermore, other objectives were:

- to know "more" about Italian cancer patients' information needs, as very little is currently known about this topic, particularly in Italy (35);
- to evaluate whether, and to what extent, our "informative manner" based on the presence of a skilled operator - located at a specialized information service provided with written and electronic information resources for patients and relatives – is actually meeting their needs.

2.2. *Methods*

In Spring 2003 a satisfaction questionnaire survey was designed to evaluate the degree of satisfaction of a sample of users. It was based on the customer satisfaction questionnaire(36) with some adjustment to the specific topic.

The questionnaire comprised fifteen closed questions, some of which required multiple answers, or multiple answers listed in priority, aimed to assess service functionality and quality from the user viewpoint. The questions concerned the users' assessment of usefulness and quality of the information received, and the skills of the staff on duty (37).

2.3. *Procedure and sample*

194 questionnaires were posted on February 2003 to those who used the CIP-LP from September 2002 to February 2003. No selection was made except regarding "end stage" cancer patients, who were not sent any questionnaires as it was felt that this would clearly be an unwanted intrusion. Some reasons for the exclusion of this group of patients are:

- a) surviving cancer patients are more likely to offer some kind of feedback than terminally ill patients;
- b) there is a need for further studies to cover the information needs of terminally ill cancer patients and their families. However, this was not the focus of this particular study.

Anonymity was maintained and forms returned by mail, by means of a prepaid envelope which had been included with the questionnaire. The objectives of the study and the instructions for filling in the form were clearly explained. The questionnaires processed were those which had arrived by April 2003.

Each item of the questionnaire was analysed. Given the small sample size, only frequencies of data have been performed.

3. **Results**

From all the questionnaires sent to patients and relatives, 113 (58% of the total), were returned completed; 75% of the respondents were women; 54% were between 31 and 50 years of age, 43% between 51 and 70 years. Two people among the interviews had died. The non-respondents were 53 % patients, 41% relatives, 6% other people.

Fifty-six per cent (56%) of the cases stated that their attention was drawn to the service via internal publicity or via “word of mouth”: people who had used the CIP-LP in the past recommended the “information space” to others (17%).

Considering those who turned to the CIP-LP, first and foremost was the patients themselves (47%).

Those who used the service did so primarily for information on general aspects of the disease, treatment and/or rehabilitation, psychological and communication aspects regarding managing their new life condition, nutrition and diet, prevention of other types of tumours or prevention of cancer in general. The presence of multiple answers which could be prioritised in terms of the type of information requested (from the most important – 1 to 4, see table 1) offers a reason for the most important topics for our users. Requests for material about nutrition and diet very often accompany other kinds of requests. We can observe an association between the type of requested information and its perceived usefulness (see table 2)

An important point to investigate was the perceived effect of the information read by patients and relatives (see table 3). In fact these users are not likely to be interested in the various health topics for professional reasons but more for personal motives, strictly related to their own disease or to the disease of their partner, relatives or friends. However, it was not the focus of this survey to pursue this aspect in depth. The patients and relatives’ quality evaluation of the material acquired from the CIP-LP represented another important question of the survey. We can see the answers from table 4. These generic answers gave us the idea of conduct another specific survey regarding the quality evaluation of the material from the users viewpoint.

From the data collected, it emerged that users using the CIP-LP reported having a “good” if not “excellent” opinion about the overall competence of the person staffing the service (see table 5). Other questions referred to the sharing of information with other family members or friends (table 6): In their answer to the second question, 57% stated they shared the information with key relatives.. Most of the patients and relatives users interviewed expressed satisfaction with the “Cancer Information Point” (table 7) and would recommend the service to other people (table 8).

3.1 Discussion

Other questions centred on the influence that the information had on the relationship between the subjects, their doctors and their family members: Fifty-seven percent (57%) declared that the information received neither influenced the relationship with the doctor nor that with family members. Seventy-two per cent (72%) of the sample nevertheless stated that the information received was of great advantage for themselves in that it led to a better understanding of the information imparted by the doctor. Forty-two percent (42%) stated that it improved their ability to ask the doctor questions which were more targeted and specific and to better understand the answer.

From the data analysis, it emerges that patients and family members, who refer to the CIP-LP of the CRO, first heard of the service mainly as a result of the Institute’s internal publicity. As already mentioned, the publicity campaign was “soft”, based on the distribution of leaflets in the Institute; this is according to the “Patient Library’s philosophy”, namely “Information helps to create a more constructive dialogue with your caregiver” (38). The choice of whether or not to use the Library is left entirely up to the patient. The service is also promoted spontaneously by each user, based upon his or her own experience.

Another investigation was conducted in Summer 2003, about the use and perception of resources of the Scientific Library. Two items concerned the awareness and sharing of the CIP-LP initiative by the vast majority of the health care workers of our Institute. The answers leave open the real possibility that they too spread the word to patients and their families about the service (39). This is verified by the increase in the number of persons referred to the CIP-LP by the medical and nursing staff of the Institute. The Library staff, on the other hand, preferred to involve the health care workers in an indirect manner: not in publicity of the CIP-LP, but in other spheres. In fact, doctors, nurses, biologists, nutritionist and psychologists were involved by the Library staff in the quality evaluation of different quality aspects of the informational material

for “layperson” (40-43) or in answering particularly complex questions of patients. As regards the evaluation of informational material received, most respondents regarded it as “good” and “excellent” (table 4) and a very small proportion (0,9%) judged it of poor quality. This question, deliberately of a general nature, was designed to obtain initial feedback on the overall perceived usefulness of the “information package” received (44;45). The fact that 93% of the patients and relative respondents judged the informational material received as positive, seems to support the idea that the quality and the content of the documents has been carefully evaluated both by the CIP-LP Staff and by the users who received it. The small proportion of respondents who did not give a positive evaluation stimulated us to implement a systematic evaluation of all documents. Ninety-five per cent (95%) of the sample expressed an opinion concerning the level of competence of the person staffing the CIP-LP as “good” if not “excellent. Nobody expressed a negative opinion on this topic (table 5).

Here again the item is of a general nature, purposely designed to gather an overall impression of the information intermediary. One may hypothesize that under this general heading are included such concepts as the staff member’s capacity for empathic and active listening, accurate interpretation of the request, careful and efficient preparation of the appropriate material for that particular requestor (46). One may also hypothesize a positive influence arising from the actual setting in which the interaction takes place: a small, yet protected area within the scientific library, a “neutral” place for patients and the family with respect to other hospital settings, yet at the same time, welcoming and reliable in terms of quality of information. Alternatively, it is also true to say that the general nature of the questions, might mask specific negative remarks that interviewees did not have not the possibility to make.

Nevertheless, after having received and read the information, the users reported that they had a better general understanding of the disease and its treatment and a feeling of greater control over the situation (see table 3). It would appear to be confirmed that an increase of “awareness” reduces the sense of bewilderment and loss of control engendered by the disease, and enhances more adaptive behaviours and a more active and fully aware participation in treatment (25;47;48).

Furthermore it emerges that the information received does not influence either the relationship with the doctor, or with the patient’s family. This is somewhat ambiguous. In our opinion the most probable hypothesis, correlating the answers, is that whoever read the material was the prime and direct beneficiary of the information. The underlying need seems to be to have something written upon which to reflect, something that will “stay with them” and that can be read and re-read and “digested” according to one’s personal time to reflect(16;46;49-51).

The high percentage of non-respondents to the interview could be related to the phase of the disease, unknown to us. In fact, coping with cancer is so difficult for some people in certain phases of the disease – for example in the relapse or after the first diagnosis communication - that they do not have any residual resources for replying to a questionnaire.

The unique characteristics of the Library for Patients are on the one hand its strengths. On the other hand such uniqueness renders it more difficult to draw exact parallels with other national or international services.

4. Conclusion

In conclusion, the above data confirm that the overall majority of the users to whom the service is directed perceives its usefulness and is satisfied: 91% of the users (patients and relatives) interviewed expressed satisfaction with the “Cancer Information Point” and 95% would recommend the service to others.

Of course this “overall usefulness” data needs further investigation. In fact we conducted a further survey to obtain patients’ detailed opinions regarding perceived quality and usefulness of the specific informational documents received by patients, relatives and friends(52). The results of the surveys so far lead one to believe that Italian patients have grown in disease awareness(25) and that health care workers are disposed to welcome this “growth”(53). The period 1998 - 2004 showed an increase in requests addressed to the CIP-LP for non-specialist information: from an

average of 300 users per year, to an average of 500 users, with about 4 topics for each person. Indeed the range of requests broadened to embrace a wider public: not just patients and their families, but also students, teachers, nurses, voluntary workers, and the general public. The collection, validation and cataloguing of information for the Italian-speaking public led to the realisation of the “Oncology Data Bank for Patients and their Families” published by our Institute in 2002 with financial support coming from the “Five Stars award”. This Data Bank was the core of “Azalea: the oncology digital library for patients and their families” - www.azaleaweb.it -, a national collaborative multicentric project supported by Alliance against Cancer (ACC), the network of Italian Institutes of Cancer Research and Treatment promoted by the Ministry of Health(34).

This study attests to the information quality and effectiveness of a service which became a model of information to cancer patients in Italy..

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Tables

Table 1

Type of information requested by users frequenting the Library for Patients

Information requested/choice	<i>n</i> =113			
	1st	2nd	3rd	4th
	%	%	%	%
On the disease in general	78	0	0	0
On prevention	5	22	0	0
On medical examinations	1	11	10	0
On therapy or physical rehabilitation	5	38	24	28
On diet and nutrition	0	20	26	21
On psychological and communication aspects	2	1	30	36
Other (even non-oncological)	5	5	10	14

Table 2

Type of information perceived as useful by users frequenting the Library for Patients.

Considered most useful information/ choice	<i>n</i> =113			
	1st	2nd	3rd	4th
	%	%	%	%
On the disease	66	6	6	6
On prevention	3	20	4	0
On medical examinations	2	9	18	6
On therapy or physical rehabilitation	12	27	20	26
On diet and nutrition	3	17	25	13
On psychological and communication aspects	4	16	18	26
Other	6	2	6	20

Table 3

Personal impact on the user of information supplied by the Library for Patients

Effect of the informational material on the requestor	<i>n</i> =113		
	1st	2nd	3rd
	%	%	%
Ability to ask the doctor specific questions	25	6	10
Better communication with the doctor	4	8	2
Clearer understanding of the illness	38	25	12
Clearer understanding of the treatment	6	32	15
Feeling of better control of the situation	8	6	18
Improved communication within the family of the disease	1		15
Feeling of greater peace of mind	3	5	7
Less confusion with respect to information found elsewhere of one's own accord (TV, press, internet)	7	3	12
No advantage from studying the information	1	1	0
Increased concern after studying the information	1	2	3
Other	1	2	2

Table 4

Users opinions regarding the quality of information received from the Library for Patients

	<i>n</i> =113 %
Very bad	0,8
Fairly good	4
Good	51
Excellent	42
No Answer	0,8

Table 5

Users opinions regarding the skill of those staffing the Library for Patients

	<i>n</i> =113 %
Very bad	0
Sufficient	4
Good	51
Excellent	43
No Answer	0,8

Table 6

Persons, other than the requestor, who read the material supplied by the Library for Patients

	<i>n</i> =113		
	1st	2nd	3rd
	%	%	%
Patient	55	0	0
Key relatives	33	57	0
Patient's friend	4	21	23
Work colleagues	0,9	2	15
Other patients	0,9	9	23
Other people	1	4	23
Nobody	1	4	15

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